Evidence-Based Treatment for First Episode Psychosis

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Building best practices with you.

On Track NY
Overview

- Introductions
- What is psychosis?
- How to explain psychosis to youth and families
- Background & context for services
- Coordinated Specialty Care
- Tips for working with individuals with FEP
- Resources
What is psychosis?

- Psychosis occurs when a person loses contact with reality. The word “psychosis” scares some people, but it actually describes an experience that many people have.
- Three out of every 100 people experience psychosis at some time in their lives, and most of them recover.
- FEP: refers to the first episode of psychosis
The Basics: Psychotic Symptoms

- **Delusions**: False personal beliefs not subject to reason or contradictory evidence and not explained by culture and religion.
- **Hallucination**: Perception of visual, auditory, tactile, olfactory, or gustatory experiences without an external stimulus and with a compelling sense of their reality.
- Disordered speech and behavior.
Schizophrenia (DSM-5)

- **Symptoms:** Delusions; Hallucinations; Disorganized speech; Grossly disorganized or catatonic behavior; Negative symptoms (two or more for a month)
- **Level of functioning declines**
- **Lasts at least six months**
Schizophrenia: Big Picture

- Occurs worldwide (~0.5-1.5%): annual incidence 15.2 per 100,000; Male/female: 1.4-1.6
- Usually develops age 16 to 25; men younger than women
- Accounts for 25% of all hospital bed days
- Accounts for 40% of all long-term care days
- Accounts for 20% of all Social Security benefit days
- Costs the nation up to $65 Billion per year

Schizophrenia in youth

- Compared to adult-onset schizophrenia, childhood onset is rare (1 in 10,000 children)
- Incidence in adolescence is not well established
  - 20% of adults with a diagnosis report onset before age 18.

Natural History of Schizophrenia
Rationale for Early Detection and Intervention

Stages of Illness

Healthy

↑

Worsening

↓

Severity of

Signs and

Symptoms

Premorbid

Prodromal/Onset/Deterioration

Chronic/Residual

End-Stage

Margin of Prevention

Gestation/Birth

10 Puberty 20

Years

30

40

50

How to Explain Psychosis to Youth and Families
What is Psychosis?
• Psychosis involves difficulty telling the difference between what is real and what is not.
• Psychosis can affect the way a person thinks, feels, and acts.
• Symptoms of psychosis are different from person to person and may even be different over time.
• The first episode of psychosis typically occurs in a person’s late teens or early twenties. Symptoms may start suddenly or develop gradually over time.

You are not alone.
• Experienced by approximately 3 out of every 100 people at some point in their lives.
• Both men and women of every race, ethnicity, culture, and socioeconomic group have these experiences.

Now what?
• Psychosis is treatable and most people recover. Discuss the young person’s experience in greater depth here.
Hallucinations cause people to hear, see, taste, or feel things that are not there. Hallucinations can seem very real. For that reason, people who experience hallucinations often have difficulty believing that they are not real. Examples of hallucinations include:

- Hearing noises or voices that others don’t hear
- Seeing things that other don’t see
- Having unusual sensations in one’s body
Delusions are beliefs that a person holds despite evidence that those beliefs are not true or accurate. Examples include:

✓ Believing that one is being watched or followed
✓ Believing that someone else is controlling one’s thoughts
✓ Believing that others want to harm you
✓ Believing that things in the environment have a special meaning just for you
Educating Youth/Family: Explaining Confused Thinking

- **Confused thinking.** One’s thoughts, and the expression of those thoughts, don’t connect together in a way that makes sense. Examples include:
  - ✓ Thoughts can seem unclear
  - ✓ Thoughts are jumbled together
  - ✓ Thoughts are racing too fast or are coming too slow
Educating Youth/Family: Explaining Changes in Behavior

- Spending more time alone.
- Having less interest in socializing with friends and family, going to work or school, or otherwise engaging in activities one used to enjoy.
- Not taking care of oneself as well as one used to (e.g., not bathing or dressing, may appear disheveled).
- Behaving in a way that doesn’t seem to fit with the situation, such as laughing when talking about something sad or upsetting, or for no apparent reason.
Educating Youth/Family: Causes of Psychosis

Psychosis could have a number of different causes, and many researchers are working to understand why psychosis occurs. Some popular ideas are:

- **Biological:** Some people are more likely to develop psychosis because of their biology or their heredity. Many cases of psychosis have been linked to problems with neurotransmitters, or the chemical messengers that transmit impulses throughout a person’s brain and central nervous system. In addition, the relatives of people who experience psychosis are more likely to experience psychosis themselves.

- **Other factors:** A person’s first episode of psychosis can be triggered by stressful events or by drug use (especially use of marijuana, speed, or LSD).
Setting the Stage: Background and Context for Services
Barriers in Current System

Stigma
Lack of Knowledge
Distrust
Insidious Onset

Help seeking

Referral from GP
Lack of Access
Unaffordability
and Inefficiency of health care

*GP - General Practitioner

Long-term dependence on mental health system

Mental Health Clinic

Police

ER/IP
Two Key Scientific Findings

- Longer duration of untreated psychosis (DUP) is associated with poorer short term and long-term outcomes
  - DUP is the time between onset of psychosis and specified treatment (e.g., antipsychotics or CSC)
- Treatment with coordinated specialty care (CSC) is associated with better outcomes
The Benefits of Early Intervention Services

- Improvements in hospital re-admission rates, symptom severity, and relapse rates
- Specific treatment components and approaches
  - Low-dose antipsychotic medications
  - Cognitive and behavioral psychotherapy
  - Family education and support
  - Educational and vocational rehabilitation
- Meta-analyses of 4 RCTs (N~800 FEP Ss) support the early treatment model (Bird, 2010)
The “Recovery After an Initial Schizophrenia Episode” initiative seeks to fundamentally alter the trajectory and prognosis of schizophrenia through coordinated and aggressive treatment in the earliest stages of illness.
NIMH RAISE Projects

- RCT to compare the effectiveness of a phase-specific intervention vs. usual community care for FEP
  - Symptomatic recovery and relapse
  - Social, academic, and vocational functioning
  - Cost effectiveness of treatment

- Implementation study to identify and surmount barriers to rapid adoption of early psychosis interventions
  - Referral and case finding strategies
  - Training and supervision of existing clinical staff
  - Financing models to support FEP treatment programs
RAISE Results

- RAISE ETP Study
  - Participants stayed in specialized treatment longer
  - Fewer psychotic symptoms
  - Experienced significantly greater improvement in quality of life (QOL)
    - Only participants with shorter DUP demonstrated a significant improvement in QOL when receiving specialized services.
  - More likely to be in work or school

- RAISE Connection
  - High engagement and retention rates
  - Significant reduction of psychotic symptoms
  - Significant improvement of social and occupational functioning
  - Rates of engagement in competitive work or school doubled
The Big Picture: Rationale

Goal is to **reduce** DUP and provide **early** intervention services to promote long term recovery and reduce disability.
Roadmap for Pathway to Care

Onset of Symptoms → Help Seeking → Referral to Mental Health Services (Could receive criterion treatment in MHS) → Referral to Early Intervention Services
Vision for Treatment: Rapid Connection

- Help seeking
- Special Early Intervention Services
Coordinated Specialty Care

Clinical Services
▶ Case management, Supported Employment/Education, Psychotherapy, Family Education and Support, Pharmacotherapy and Primary Care Coordination

Core Functions/Processes
▶ Team based approach, Specialized training, Community outreach, Client and family engagement, Mobile outreach and Crisis intervention services, shared decision making

OnTrackNY is an innovative treatment program for adolescents and young adults who recently have had unusual thoughts and behaviors or who have started hearing or seeing things that others don’t. OnTrackNY helps people achieve their goals for school, work, and relationships.
What does OnTrackNY Offer?

- The goal of OnTrackNY is to provide hope and effective treatment so that young adults with psychosis can achieve their goals in life.
- Rather than working with just one mental health professional, we offer a collaborative team approach that relies on everyone’s strengths and energy.
- The young adult with psychosis is a member of the team, along with the family and other mental health professionals.
- A team leader helps to keep everyone on the team working together toward the young person’s recovery.
- We use a “shared decision making” approach to be guided by the young person’s preferences.
Treatment offered by OnTrackNY

- A comprehensive assessment of the young person’s’ personal recovery goals to inform and guide treatment.
- Treatment and support from team members including a doctor, mental health professionals, and supported employment and education specialists who have worked with people recovering from psychosis.
- Psychoeducation and support for family members focused on providing information about psychosis and teaching family members how to assist young people in their recovery.
- Support from a supported employment and education specialist with expertise in helping young people identify and reach their school and work goals.
- Assistance with strategies for building healthy relationships and coping with problems in positive ways.
- Treatment and support for drug or alcohol problems.
OnTrackNY Team Intervention

Outreach/Engagement

- Evidence-based Pharmacological Treatment and Health
  - Supported Employment/Education
  - Recovery Skills (SUD, Social Skills, CBT)
  - Psychotherapy and Support
  - Family Support/Education
  - Suicide Prevention

Peer Support

Recovery Skills

Shared Decision Making

4.0 FTE
Eligibility Criteria

- **Age:** 16-30
- **Diagnosis:** Primary psychotic disorder. Diagnoses include: Schizophrenia, Schizoaffective disorder, Schizophreniform disorder, Other specified schizophrenia spectrum and other psychotic disorder, Unspecified schizophrenia spectrum and other psychotic disorder, or Delusional disorder
- **Duration of illness:** Onset of psychosis must be ≥ 1 week and ≤ 2 years
- **New York State Resident**
Eligibility Criteria: Exclusionary Factors

- Intellectual Disability (IQ < 70) or Autism Spectrum Disorder
- Primary diagnosis of substance-induced psychosis, mood disorder with psychotic features, or psychosis secondary to a general medical condition
- Serious or chronic medical illness significantly impairing function independent of psychosis
Eligibility Criteria

OnTrackNY teams provide services to all referred individuals meeting clinical admission criteria, without wait lists and regardless of their insurance status or ability to pay.
Referral Process

Referral/Screening
- Initial Call
  - Self/family member
  - Provider
  - Other professionals

Follow-up and Evaluation
- Pre-evaluation activities
  - In person visits
  - Multiple phone calls

Intake
- Enrollment/Intake
- Re-direct referral if individual doesn’t agree
Kaitlyn’s Story

A year and a half ago Kaitlyn started experiencing psychosis (hearing voices and feeling paranoid) and experienced several traumatic family events. Although high school had gone well, she was struggling in college and thinking about dropping out when she was hospitalized for a full month because of the psychosis.
Kaitlyn’s Story: Engagement

- The OnTrackNY team struggled to engage with Kaitlyn for over four months. The team tried many strategies including having the team’s Peer Specialist meet her in the community and at her home, arranging meetings with the Supported Education and Employment Specialist (SEES) to discuss vocational goals, and working with her to identify effective coping skills. Although she kept coming to her appointments, her slow progress was disappointing to her, her family, and even the treatment team at times.

- Around this time, the OnTrackNY team’s SEES was able to connect Kaitlyn with a local retail employer who hired her for a part-time stock associate position. Not too long after this, Kaitlyn seemed to have a boost in confidence and started talking with the team about the possibility of returning to college, even though the idea was frightening to her.
Fast forward eight months. Kaitlyn has been managing a full college course load, she is earning mostly A’s in her classes, she is interacting with friends again, dating, and forming new friendships. She showed up at the clinic at the end of her semester to excitedly announce to the team that she had made the dean’s list!

Kaitlyn and the team worked incredibly hard together over these past eight months. She was meeting with her Primary Clinician for therapy and skills building, trying various medications with the team Psychiatrist before finally finding one that she felt worked for her, she attended groups run by the peer specialist, and she sees the team’s nurse every month to receive an injectable medication. While she meets with the nurse they also talk about dating and the importance of sexual health. Kaitlyn’s family has also benefitted from her involvement in OnTrackNY. Her uncle, who has been a giant support in this process, attends family groups and meets occasionally with other team members for family consultation.
Kaitlyn’s Story: Discharge

- Kaitlyn and her treatment team are preparing for her graduation from OnTrackNY, setting up mental health services for her once she no longer has the supports of the OnTrackNY team, and most importantly identifying how she will continue to progress in her life and career goals.
General Tips for Working with Individuals with FEP
Tips for Engagement

- Understand what they are seeking by learning what is going on for them at this time.
- What programs/kinds of treatment have they already (recently) tried connecting with? What were the challenges?
- Provide information about services based on the above
- Connect such exploration with detailed examples about services might be able to help (e.g., getting a job, making friends, etc.)

- **Common traps:** Talking about the program too mechanically; asking too many detailed questions in order to begin determining eligibility.
Tips for talking to youth and family

- During these early stages of engagement, it is especially important to be mindful of the young person’s experience of what may be happening and to adopt his/her language in the conversation.
- Important to do this with family also
- Understand cultural context and incorporate as much as possible
Person says, “I am not psychotic.” How should you respond?

- Ask them what they think is the problem and what might be helpful. Then try to communicate how services can help given their understanding of the problem. Do not try to convince a person that he/she is psychotic. Instead, try to find common ground.
Factors That Contribute to Recovery

- Clinicians play a vital role in early detection of first episode psychosis, connecting people to the right care and conveying hope for recovery.

- Specialized early intervention services improve clinical and functional outcomes by focusing on the individual’s goals to guide treatment decisions. Clinicians follow a shared decision-making framework to make decisions about treatment, encourage family involvement, and help the individual develop skills to manage symptoms and prevent relapse.
Importance of Family Collaboration

- First Episode Psychosis often affects young people who are living in the family home.
- Families are often the first to notice the changes associated with symptoms of psychosis and can be key players in seeking help.
- Family members may not understand why the changes they see in their loved ones are occurring, or how to help. Recognizing that families can be a valuable resource in getting individuals to appropriate care and supporting treatment engagement is key.
- Coordinated Specialty Care programs provide families with the education and support they need.
Resources

▷ www.ontrackny.org

For young adults and family members

**Links to Mental Health Resources**
- Center for Practice Innovations
- National Alliance on Mental Illness National
- National Alliance on Mental Illness NYC Chapter
- First Episode Psychosis Recovery Stories
- SBIRT & Screening App
- Employment Resource Book
- Voices of Recovery Videos
- NASMHPD Information for Providers

For providers and organizations

**OnTrackNY Team Manuals**
- Team Manual
- Medical Manual
- Primary Clinician’s Manual
- Supported Employment and Supported Education Manual
- Recovery Coaching Manual
- Outreach and Recruitment Manual
- Voices of Recovery Manual
- Peer Specialist Manual
- Family Manual
- Delivering Culturally Competent Care in FEP
- Treating Cognitive Health Manual

**Links**
- Voices of Recovery Videos
- First Episode Psychosis Recovery Stories
- Center for Practice Innovations
- Learning Management System
- New York State Psychiatric Institute
- New York State Office of Mental Health
- Data Collection Forms
- Nathan Kline Institute for Psychiatric Research
- LGBT Module 1: LGBT 101
- LGBT Module 2: Identity Development
- LGBT Module 3: Affirmative Health for LGBT Individuals with Psychosis
Sebastian - Finding Harmony through Music

Just before starting college, Sebastian began having unusual auditory and visual experiences. With the support from OnTrackNY and using music to cope, Sebastian gained the confidence to share his story to help others. Sebastian’s mother also shares her perspective on recovery and being part of OnTrackNY.

'D' - Learning to Prioritize Your Mental Health

Skittles - Laying the Foundation for Recovery

In this video, Skittles speaks about hearing voices and how her passion for makeup has helped her cope and express herself. Skittles also talks about her initial apprehension to open up about her psychosis and the role OnTrackNY played in her openness to receive help.

Anna - Drawing the Path to Recovery

Anna shares her own journey and how OnTrackNY has played a role in her recovery.
Other Resources

‣ NYC Start
  • [https://www1.nyc.gov/site/doh/health/health-topics/crisis-emergency-services-nyc-start.page](https://www1.nyc.gov/site/doh/health/health-topics/crisis-emergency-services-nyc-start.page)

‣ Outpatient programs/clinics
  • Lenox Hill Early Treatment Program & Long Island Jewish Hospital Early Treatment Program
    • [https://www.northwell.edu/behavioral-health/programs-services/early-treatment-program](https://www.northwell.edu/behavioral-health/programs-services/early-treatment-program)

‣ Mount Sinai clinical and research program for youths 12-30
  • [www.icanfeelbetter.org](http://www.icanfeelbetter.org)

‣ Center for Prevention and Evaluation Cope
Thank you!

Any questions about the content of the presentation, please email:

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